

VOL. I. NO. 5

PENNSYLVANIA DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

JAN/FEB 1978

Developmental Disabilities Planning Council Meeting



Council meeting at Taminent September 30, 1977. Left to right: Margot Mor, DD Staff; Carl Saylor, George Orwig, Judith Body, Dan Torisky, Council members; Barry Newill, staff; Lee Rubin, Executive Director; Arthur Berger, Past Council Chairperson; Mary Rita Hanley, Chairperson, and Marvin White, Council.

(Photo courtesy of Walt Howat)

The Pennsylvania Developmental Disabilities Planning Council met December 1, at the Sheraton-Harrisburg Inn.

Reports were given by the following chairpersons relative to the ongoing activities of their respective committees: George Orwig, who has succeeded Mary Rita Hanley as Chairperson of the Planning Committee upon her assumption of the chair of the Council; Carl Saylor,

Community Living Arrangements; Daniel Torisky, Implementation Review Committee; and Walter Howat, Public Awareness Committee.

John Hagan, Director of the Commonwealth's Bureau of Vocational Rehabilitation, described BVR's activities on behalf of developmentally disabled citizens.

Of 21,000 BVR average permanent placements of individuals in jobs per year,

during the past year BVR placed 1219 people with mental retardation, 300 with cerebral palsy, and 119 with epilepsy. He cited a special program in computer programming at the Wharton School of the University of Pennsylvania in which 12 students with cerebral palsy have been trained. Four of these are presently working and four are in the process of being placed. Pennsylvania has also been in the forefront of developing sixteen cardiac rehabilitation units with equipment including bicycle odometers and treadmills. He estimated the average cost of rehabilitation per individual as \$1700 per year. BVR served 139,000 people last year and has 39 working agreements with other agencies.

Also discussed in depth were the Program Regulation Guidelines issued in September by the Developmental Disabilities Office of HEW to assist State Agencies, Councils, "and all other entities and authorities in the State government and in the private sector who are in any way involved or concerned with matters related to the administration of the DD State Plan."

Gary Makuch, Director of the Bureau of Special and Compensatory Education, Pennsylvania Department of Education, discussed P. L. 94-142 and the effect of Pennsylvania Senate Bill 1161 on the special education needs of Intermediate Units. Council has gone on record as opposing that part of the Bill which would involve special education cutbacks.

Mary Rita Hanley Chairperson of Pennsylvania DD Council

Mary Rita Hanley, President of the Pennsylvania Association for Children with Learning Disabilities, was welcomed as the new Chairperson of the Pennsylvania Developmental Disabilities Council by Milton Berkes, the Governor's Special Assistant for Human Services, at the Council's meeting October 27, 1977, at the Penn-Harris.

Mrs. Hanley succeeds Arthur Berger, Esq., who has served as Council Chairperson for the past year.

Mrs. Hanley's philosophy is expressed in a recent letter to DD Council members in which she charged: "Regardless of your present position or role, as a Council member you are an advocate and your responsibility to this Council and to those it represents obliges you to diligently work for all developmentally disabled persons. We cannot afford parochialism and its limitations. Neither can we function effectively if we are consumers against agencies or vice versa....our newly born Developmental Disabilities Advocacy Network (DDAN) is a child of the Council which will make the Council's efforts a reality for those persons in need. While the fiscal structure is such that DDAN is independent of the Council, these two bodies must work together if advocacy is to have any meaning in Pennsylvania.

"Regardless of the nature of their handicap our fellow human beings must still in this enlightened era fight for their rights to be educated, to live decently, to earn a living, to enjoy, to love, and to share the good things that the rest of us take for granted. We must pledge ourselves to every Pennsylvanian whose life is overshadowed by a handicap.

Plan for Nationwide Action on Epilepsy

Of the conditions embraced by the term "developmental disabilities," none is clouded by more widespread

misunderstanding -- even today -- than is epilepsy.

Epilepsy -- "the hidden handicap"

Despite current ignorance and misunderstanding, epilepsy, as a medical entity, was described by Hippocrates circa 400 B. C. Julius Caesar, whose literary and socio-political talents outshone his brilliant career as one of history's greatest and most ruthless military strategists, is known to have been an epileptic. It can be speculated with reasonable certainty that amongst the unknown numbers of innocents burned at the stake throughout the Middle Ages as possessed of the Devil and pursued through the days of the Salem witch-hunts in our own country, there was more than a token number of epileptics.

Normal one minute, out of control the next, the person with epilepsy has been han dicapped not only by the unpredictable and devastating character of his disorder but also by the consistent rejection of a society which fears what it does not understand. Some, with seizures reasonably controlled, lead nearly normal lives. Others need strong support even to survive.

On July 29, 1975, the 94th Congress passed Public Law 94-63, an amendment to the Public Health Service Act. Among its provisions, the law specified that the Secretary of Health, Education, and Welfare should establish a Commission for the Control of Epilepsy and Its Consequences: a nine-member commission was appointed in the Spring of 1976.

The law provided four specific mandates for this Commission:

- 1. To make a comprehensive survey of medical and social management of epilepsy in the U. S.
- 2. To investigate and to make recommendations about the proper roles of Federal and state governments and of national and local public and private agencies in research, prevention, identification, treatment, and rehabilitation of persons with epilepsy.
- 3. To develop a comprehensive national plan for the control of epilepsy and its consequences based on the most

thorough, complete, and accurate data and information available.

4. To transmit to the President, to the Senate Committee on Labor and Public Welfare, and to the House Committee or Interstate and Foreign Commerce report detailing the findings and conclusions of the Commission, togethe with recommendations for legislation and appropriations.

Epilepsy is not a disease at all -- it is a symptom of some other problem. Sometimes the problem can be identified and corrected -- a brain tumor or some form of metabolic imbalance, for example -- but often it cannot be identified. All epileptics do have one feature in common -- a disturbance in the normal pattern of the electrical activity of the brain. Such disturbance is sudder and episodic; frequently recurrent. It car involve impairment of thought and awareness or responsiveness, or both, and may involve convulsions or automatic movements.

Prior to 1970, seizures were divided into four main sub-types: Grand mal Petit Mal, Psychomotor, and Akinetic Myoclonic.

The Commission found it extremely difficult to determine the number o people in the U. S. who have epilepsy For one reason, epilepsy can be hidden Except during a seizure, nothing indicates that a person has epilepsy. Because the label of "epilepsy" is an effective barries to employment, education, and a normalife, many keep the condition a secret.

In addition to identification (the most reliable figure indicates 6.57 per thousand), definition posed a problem Does one seizure mean epilepsy?

The Commission's preliminary report submitted in August, 1977, calls for the development of a Comprehensive Epilepsy Service Network under the aegis of the National Institute of Neurological and Communicative Diseases and Stroke and establishment of 50 Epilepsy Family and Individual Resource Teams. A sophisticated Action Plan, Budget, and Strategy for Implementation is recommended.

The Commission found that, although every state Developmental Disabilities program has a federally mandated responsibility for planning for epilepsy, few states have laws that give responsibility for that epilepsy planning

Continued on page 4

Task Force on the Definition of Developmental Disabilities

The definition of Developmental Disabilities originally cited in P.L. 94-103 refers to a disability which:

- "(A)(i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism:
- (ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or
- (iii) is attributable to dyslexia resulting from a disability described in clause (i) or (ii) of this subparagraph;
- (B) originates before such person attains age eighteen;
- (C) has continued or can be expected to continue indefinitely; and
- (D) constitutes a substantial handicap to such person's ability to function normally in society."

Norman V. Lourie, Executive Deputy Secretary of the Commonwealth of Pennsylvania Department of Public Welfare, has served as Chairperson for the National Task Force, a responsibility to which he has brought a lifetime of distinguished dedication to the enhancement of human services.

DRAFT OF THE RECOMMENDED APPROPRIATE BASIS FOR THE DEFINITION OF DEVELOPMENTAL DISABILITIES

The following is the draft recommendation of the National Task Force on the Definition of Developmental Disabilities for the appropriate basis for the definition of developmental disabilities:

For purposes of the Developmental Disabilities Act, a developmental disability is a severe, chronic disability of a person which:

- 1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
- 2. is manifest before age 22;

- 3. is likely to continue indefinitely;
- 4. results in substantial functional limitations in three or more of the following areas of major life activity:
 - a. self-care,
 - b. receptive and expressive language,
 - c. learning,
 - d. mobility,
 - e. self-direction,
 - f. capacity for independent living, or
 - g. economic self-sufficiency; and
- 5. reflects the need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are
 - a. of lifelong or extended duration and
 - b. individually planned and coordinated.



Norman Lourie, Executive Deputy Secretary of Pennsylvania Department of Public Welfare, has been Chairperson for the National Task Force on Definition of Developmental Disabilities.

WHO IS INCLUDED AND WHO IS EXCLUDED FROM THE PROPOSED DEFINITION: A COMPARISON BETWEEN THE EXISTING AND THE PROPOSED DEFINITIONS

The proposed definition was intended to cover everyone currently covered under the definition and was also intended to add a small number of other individuals with similar characteristics.

The majority recommendation of the Task Force was that the appropriate basis for the definition should be the characteristics of the disability and its impact on the person's ability to function, not the specific conditions or diagnostic categories of the individual with a disability. The proposed definition, therefore, was intended to cut across a wide number of specific diagnostic conditions to include a subgroup of individuals within these categories of conditions who met certain criteria as spelled out in the recommended wording.

DRAFT OF MINORITY REPORT

Minority Report of Members of the National Task Force on the Definition of Developmental Disabilities

Eleven members of the National Task Force on the Definition of Developmental Disabilities agree with and support the proposed redefinition of "developmental disability" except Part #1 which states "is attributable to a mental or physical impairment or combination of mental and physical impairment." The wording in Part # 1 has the effect of dropping all identifiable categories of disability from the definition. The eleven signers of the minority report, the majority of whom are or have been responsible for interpretation and implementation of the developmental disabilities program at the state and local levels, do not believe that the program can be successfully administered without identifiable categories and disability. A generic definition necessitates endless interpretation of who is or is not developmentally disabled and serves the potential for not serving those most in need of services.

This minority report proposes the following substitution for Part #1:

"Is attributable to mental retardation, cerebral palsy, epilepsy, or autism; or

Continued on page 4

Nationwide Action Cont'd.

to a specific agency. A need was cited for leadership at the Federal level, within the Office of Developmental Disabilities, to give emphasis to planning for persons with epilepsy.

Most states reported non-categorical use of Developmental Disabilities funds for persons with epilepsy. The amount of Developmental Disabilities grant money used for epilepsy varies from a reported \$1,430 (Idaho) to \$306,000 (New York). A substantial grant during the 1975-76 fiscal year was awarded to Pennsylvania Division, Epilepsy Foundation of America.

Task Force Cont'd.

is attributable to any other condition of a person similar to mental retardation, cerebral palsy, epilepsy, or autism because such condition results in similar impairment of general intellectual functioning or adaptive behavior and requires treatment and services similar to those required for such persons."

Therefore it is the position of the signers of this minority report that the definition not be based on the vague and all-inclusive phrase "mental or physical impairment," but rather that the existing categorical disabilities named in the act be retained with a strong emphasis on serving other individuals who meet the criteria of similar impairment requiring treatment similar to those required by categorical disabilities named in the definition.

Pennsylvania State Plan Available

The 1978 Fiscal Year State Plan for Pennsylvania is off the press and available to interested individuals and organizations by request to: State Plan, Governor's Council on Developmental disabilities, 2101 N. Front Street, Building #4, Harrisburg, Pa. 17110.

Pilcop Conducts Regional Section 504 Workshops

Public Interest Law Center of Philadelphia has been conducting workshops for consumers and advocates in major communities throughout the Keystone State to familiarize them with the ramifications of the Section 504 Regulations (of the Rehabilitation Act of September 26, 1973) signed by Secretary of Health, Education, and Welfare Joseph Califano on April 28, 1977.

In language almost identical to Title VI of the Civil Rights Act of 1964 prohibiting discrimination on the basis of race, color, or national origin, and Title IX of the Education Amendments of 1972 banning discrimination on the basis of sex, Congress mandated:

"No otherwise qualified handicapped individual in the United Stated...shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal assistance."

Supported in part through grants by the Pennsylvania Developmental Disabilities Planning Council and the Developmental Disabilities Advocacy Network, PILCOP's workshops have been designed to train aspiring advocates to cope with resistances which can be anticipated in response to the 504 Regulations which cover every state, county, local government program, and every private agency which receive funds directly (or through the state) from HEW, including school districts, mental health/mental retardation units, colleges, universities, hospitals, and neighborhood health clinics.

The regulations provide the framework for bringing about such fundamental changes as removing architectural barriers, providing effective communication for the blind and deaf, and accommodating the needs of all

disabled people at the work place and in the classroom.

The workshop was organized around role-playing sessions to teach consumers and advocates to use Section 504 with optimum effectiveness in conference and negotiations with government officials, school and hospital administrators, employers, and other program heads in order to obtain needed services.

United Cerebral Palsy Annual Meeting

The 26th annual meeting of United Cerebral Palsy of Pennsylvania was held at the Hotel Hershey, Hershey, November 3-5, 1977.

The Honorable Frank S. Beal, Secretary of Welfare of the Commonwealth, gave the Awards Dinner address.

Nicholas Kordopatis, President of the Board of UCP of Pa., and Vice-President of Union Bank of Easton, was presented with a Senate Resolution commending him for his outstanding volunteer efforts by State Senator George W. Gekas.

Working sessions at the meeting were addressed by John A. Hagan, Director of the Bureau of Vocational Rehabilitation, Walden M. Holl, Executive Director of the Allegheny Lutheran Home and Lutheran Social Services of the Allegheny Region and President of Cambria County Health and Welfare Council, and Thomas C. Slater, Director of Slater Laboratories.

Also speaking to participants was Dr. Gary Makuch, Director, Bureau of Special and Compensatory Education, Pennsylvania Dep't of Education, who described some of the aspects of Pennsylvania's implementation of P. L. 94-142 and the logistic intricacies of funding programs for handicapped children. Mel Knowlton, Director, Bureau of Community Programs, Pennsylvania Dep't of Public Welfare, Office of Mental Retardation, discussed the present status and some of the problems of the Community Living Arrangements program.

Legislation of Interest

by United Cerebral Palsy of Pennsylvania 1719 North Front Street Harrisburg, Pennsylvania 17102

Senate Bill 959

Will be reported from the Public Health and Welfare Committee for consideration by the Senate and reference to the Appropriations Committee. This bill would establish special care centers across the state and appropriate transportation to provide care and treatment for high risk maternity patients and for newborn infants suffering injury or illness including medically diagnosed congenital defects and birth abnormalities.

House Bill 1703

Would expand the Motor Vehicle Code section on parking for vehicles bearing license plates issued to handicapped persons. This bill would authorize PennDOT to issue "handicap placards" for the use of handicapped persons which would be transpertation of that person. As a result, the driver of that vehicle would not be liable for parking for a period of 60 minutes in excess of the legal parking period. By Zwikl, McLane, and nine others. Transportation Committee.

House Bill 1707

A companion bill to HB 1703, would expand the definition of persons entitled to apply for handicapped plates to include "....any person who: (1) does not have full use of a leg or both legs or an arm or both arms or otherwise has a physical mobility limitation;"

Transportation Committee.

House Bill 1708

Would expand "The Fish Law of 1959" to waive the requirement of a fishing license for those persons "....who are so severely handicapped that they are unable to cast or retrieve a line or to bait hooks and remove fish or to persons who do not have the full use of a leg or both legs or an arm or both arms or are blind;". By the above 11 legislators. Games and Fisheries Committee.

Implementation Task Forces Members

EDUCATION:

Harold Godwin, Chairman; Raymond D. Bogardus, Richard Bosserman, Donald Gallion, S. Ellsworth Haigh, Jr., Donna Schaeffer, George F. Tillson. Consultants: Betty Broecker, Stephen Margolis, Sandra Rubin, Charles B. Sauder, Ted Vollrath, Ronald Weitzel.

HEALTH

Dr. John Bartram, Chairman; Mr. and Mrs. James Burkholder, Dr. Anne Keller, Dr. Ralph Rusynyk, Dr. Thomas E. Strax, Elizabeth Tredway.

Subcommittee on Dentistry; Dr. Rusynyk, Chairman; Dr. William Binns, Dr. Eugene Czarnecki, Dr. Robert Runzo, Dr. George Saylor.

Subcommittee on Professional

The Grand Stand - Planner

A Joint Bi-Monthly Publication of the Governor's Committee for the Physically Handicapped Francis X. Coyle, Chr. George W. Severns, Jr. Publications, Chr.

and the

Developmental Disabilities
Planning Council
Mary Rita Hanley, Chr.

GOVERNOR'S OFFICE
The Honorable Milton J. Shapp
Governor of Pennsylvania

John H. Snyder, Governor's Advocate for the Physically Handicapped

Lee Rubin, Executive Director Pennsylvania Developmental Disabilities Planning Council

Circulation 20,000 Copies

Training: Dr. William H. Jeffreys, Barbara Sherman, Dr. Philip Spergel.

ARCHITECTURAL ACCESSIBILITY

Robert Burdett, Chairman; George Brenoy, Ruth Brenyo, Honorable Gary Crowell, Col. David Farr, John Fuehrer, Joseph Margalis, Patricia McGrath, Samuel Zionts.

DEINSTITUTIONALIZATION COMMUNITY LIVING:

David Halliwell, Chairman, Harry Guise, Jane Jones, Dorothy Moser, Jean Potak, Earl Power, Mel Knowlton (consultant).

TRANSPORTATION

Dr. James Miller, Chairman; Kenneth Dallmeyer, Irv Karpe, Stephen Keiper, John Sergi, Sieglinde Shapiro.

SOCIAL SERVICES:

Dr. Richard Estes, Chairman.

Subcommittee on Service Delivery:
Russ Gland, Chairman; Albert Bussone,
Judith Hirshwald, Claire McGrory, Aram
Terzian, Jerry Wettstone.

Staff Assistants: Judith Fields, Linda Graver, Sharon Jachter, Reva Rose, Terri Swantic.

Subcommittee on Information and Referral System: Bonnie Gellman, Chairman; Sanford Alexander, James Vagoni, Shirley Viehman.

Staff Assistants: Ralph Dumaran, Liz Kirs, Alberta Orr.

News from...

The Governor's Conference on Handicapped Individuals Implementation Process

Meeting Nov. 14

The implementation Committee of the Governor's Conference on Handicapped Individuals met on November 14, 1977 at the Easter Seal Society for Crippled Children and Adults Headquarters in Middletown. Task Force Chairmen presented status reports of their Committees' activities, discussed current projects and, in some cases, presented recommendations for consideration by the Implementation Committee. The carefully detailed organized content of the reports indicated hard work and creative thinking on the part of the Task Force members.

TASK FORCE HIGHLIGHTS

ARCHITECTURAL ACCESSIBILITY TASK FORCE

Patricia McGrath reported on several projects for the Chairman Robert Burdett. The Task Force has persuaded the McGraw-Hill Publishing Company to consider the inclusion of equipment and standards for the disabled in their next edition of SWEETS CATALOG, a compendium of equipment standards and material for builders. The Task Force plans to promote the development of a manual for architectural accessibility standards similar to those available in Ohio, North Carolina, and New Jersey. The Task Force is also considering ways to ensure that Section 504 of The Rehabilitation Act of 1973 are consistently interpreted at the state level. The group is also beginning to systematically analyze the shortcomings of Act 235, The Legislation for Architectural Accessibility in Pennsylvania.

EMPLOYMENT TASK FORCE

Harold Godwin, Chairman, noted that

the Bureau of Vocational Rehabilitation, the Bureau of Employment Services, and the Office for the Visually Handicapped had already begun to respond to the recommendations made at the Governor's Conference in Hershey. Many of the services recommended already exist. The Task Force and State Government representatives are currently working on a summary which will identify and correlate the services offered by these three agencies. The Implementation Committee will consider the most expedient way of publicizing these services and interactions when the summary is completed in early 1978.

Task Force on Health Services and Training of Health Professionals

Dr. John Bartram reported that his Task Force was attempting to define the ideal working relationship between the Department of Health and the Department of Education in the care of the disabled preschool and school aged child. Current therapeutic and medical services and departmental interests overlap, and a careful definition of responsibilities is needed before an ideal program can be set up. The ideal program will build on current programs in both departments and also attempt to fill the gap.

He reported that the Dental Subcommittee, Dr. Ralph Rusynyk, Chairman, presented a 70-page report on availability of care for disabled individuals' needs, priorities and recommendations for training dentists for work with the disabled. The report listed dentists in the Commonwealth of Pennsylvania who will provide care to the disabled. The list is on file in the Governor's Office for Human Resources (717 783-8348).

The Implementation Committee

supported two Health Task Force Recommendations:

Recommendations:

It is suggested that the Secretary of Health be urged to take whatever steps may be necessary to bring about fluoridation of the various supplies of drinking water in Pennsylvania, and to overcome vigorously whatever blocks may currently exist to delay this step toward decreasing disabling and handicapping conditions secondary to dental caries.

The Implementation Committee should give immediate support to the ongoing compaign to immunize children against preventable contagious diseases that may result in disabling, crippling and handicapping conditions.

The Implementation Committee should consult the Division of Communicable Disease Control in the Health Department to ascertain the types of support needed to publicize and implement the project.

SUBCOMMITTEE ON SEXUALITY AND THE DISABLED

A special Subcommittee on Sexuality and the Disabled is being organized by Dr. Dorothea Glass and the staff of the Moss Rehabilitation Center. Recommendations concerning appropriate sex education for the disabled, public awareness of sexual rights of the disabled, and skilled genetic counseling will be developed. Moss Rehabilitation Center has had extensive experience in developing workshops and teaching programs in this field.



Dr. Richard Estes (center) chairman of the Social Service Task Forces discusses with committee members The Implemention Process.

OPPORTUNITY FOR VOLUNTEER SERVICE

The Implementation Committee welcomes staff assistance from college or graduate students living in the Philadelphia or Harrisburg area. Anyone interested in a career in human services, government or public health might find the work intersting and rewarding. Volunteers could work for any amount of time from one week to a month to six months. Contact John H. Snyder, 717 783-8348 for details.

SOCIAL SERVICE TASK FORCE

Dr. Richard Estes described the complicated charge confronting his Task Force which brought about the formation of several subcommittees. He acknowledged the vital staff work done by graduate students in the School of Social Work at the University of Pennsylvania.

The Service Integration Subcommittee, Russ Gland, Chairman, has been asked to develop an ideal model for delivery of services to the disabled, after analyzing the shortcomings and strengths of existing models. The analysis will cover both administration and

management and identification of needed services which do not yet exist.

The Information and Referral Subcommittee, Bonnie Gellman, Chairman, is gathering information on present information and referal systems in the state and elsewhere. These systems are being scrutinized for relevance, accuracy and cost. The committee is considering the initial site where the information is collected, the dissemination of the data at a state, regional and local level, and the form in which the information should be presented to the consumer, by publication, telephone or computer.

The Social Service Task Force suggested that an additional 800 number and telephone line be connected to the Governor's Action Line to enable disabled individuals to obtain information about services and help with problems. Francis X Coyle, Director, Governor's Ofc. Human Resources, and Advisor to the Implementation Committee stated that the cost of the addition of another number and line prevented the installation at the present time, but that such installation could be considered if the demand were demonstrated. He encouraged disabled individuals to use the

present Governor's Action Line. David Halliwell, Executive Director of the Sheltered Workshop of York County, announced that his organization would donate a TTY teletypewriter for use in the Governor's Action Center.

GOVERNOR'S ACTION LINE

Anyone wishing information about specific services for the disabled or help with problems is encouraged to call 800 932-0784, the Governor's Action Center.

Persons with hearing impairments will be able to use the number after a TTY teletypewriter is installed in January, 1978

If you get a busy signal, keep trying!

COMMENTS NEEDED

The Implementation Committee discussed at length the following recommendation from the Health Task Force.

It is recommended that prospective in reports, publicity, communication and general usage, the adjective and noun handicapped be replaced by the noun disability and the adjective disabled, whenever proper usage so directs. Appropriate definitions acceptable to consumers in our group are:

disability: some quality either physical, emotional or mental that an individual may be lacing when compared to standardized norm for that particular trait.

<u>handicapped</u>: functional activity cannot be performed because of one or more disabilities.

The Implementation Committee would like to receive the thoughts of the disabled and those who work with and for them on this recommendation. Please mail your comments to the Governor's Office for Human Resources 504 State Street Building, N.W. corner Third and State Street, Harrisburg, Pennsylvania 17101.

Continued Compliance

Excerpts from Statement by
David S. Tatel, Director
Federal Office for Civil Rights – HEW

Our contacts with school, college, and hospital administrators indicate a growing misunderstanding of at least one part of the regulations issued under Section 504 of the Rehabilitation Act of 1973. Section 504 prohibits discrimination against qualified handicapped persons in federally assisted programs.

Specifically, the notion that these institutions must eliminate all architectural barriers in three years has gained widespread belief. This is erroneous. The regulations do not require the elimination of all architectural barriers.

The regulations do require that enough buildings or parts of buildings be made accessible so handicapped persons can participate in the activity being supported by HEW funds. While a part or percentage of an institution's facilities must be accessible, there is no prescribed number or percentage that is required.

The object is to make the programs of an institution accessible, not every classroom or dormitory room.

It has been difficult to get attention focused on program accessibility because some people seem to skim over the regulations and explanatory materials and start fretting about the widening of thousands of doors or installation of high and low water fountains in every facility at every conceivable point. A result of the misunderstanding is a rising exaggeration of the potential costs of making programs accessible.

Institutions that over-estimate what is required and elect to do nothing at all because of this misunderstanding will do a disservice to themselves and to handicapped persons who seek a way in the door but who do not ask for a magic flying carpet.....

When institutions begin actual development of the transition plan to

assure program accessibility, they will in all likelihood discover the requirements on them to be less burdensome than they have anticipated.

Handicapped persons will prove an invaluable resource to the institutions as they plan for change. A thorough understanding of the regulations, use of the experience and technology available in dealing with the needs of handicapped persons, and some ingenuity in planning will substantially decrease the amount of money needed to provide program accessibility.

The regulations emphasize the use of nonstructural changes to assure accessibility. One such method involves the relocation of courses in which handicapped students have enrolled to newer buildings that are already accessible. Using this method, a large midwestern university which has approximately a third of its buildings accessible, is able to accommodate the needs of all of the handicapped students.

Another technique is the use of aides in libraries. Stacks in the libraries of some older institutions are on upper floors with no elevator access. In this situation, the institution can use aides to conduct the search in lieu of installation of lifts. The aides can locate and deliver the needed books to the accessible main floor of the building. Use of aides would constitute compliance with Section 504 as long as they are available during the operating hours of the library.

You may obtain additional information from the Office of Public Affairs, Office for Civil Rights, Department of Health, Education, and Welfare, Washington, D.C. 20201. Telephone: (202) 245-6480.

TRANSITION PLANS PAST DUE

by John H. Snyder Governor's Advocate for the Physically Handicapped

Section 504 states that: "No otherwise

qualified handicapped individual in the United States...shall solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

The final Section 504 regulations were issued for all recipients of funds from HEW which include, elementary and secondary schools, colleges, hospitals, social service agencies, and in some instances, doctors. The Governor has called upon all State agencies to come in compliance with 504 regulations.

I would hope that all private agencies were taking steps to comply to the regulations as quickly as possible as well. Not only should these changes affect the physically accessibility of building but affect the attitudes of institutions and in dividuals toward the disabled/handicapped person. Laws do not in themselves make change, but attitudes, feelings and love for our fellow man.

Not the letter of the law, but the intent of the regulations implore upon all who should be complying to the 504 regulations to have disabled/handicapped representatives from the community-at-large participate in the work of compliance and evaluation committees to assist in understanding and help in adapting.

These individuals are from all over the state, therefore, no agency, school or medical service should have any excuse that they did not have the disabled/handicapped involved in their evaluation or planning.

If your facility or agency, in its efforts to comply with the 504 regulations needs assistance in locating a qualified handicapped consumer from your community to serve on a consultant basis, please contact my office at (717) 783-8348 and we will help you find the person you need.

of Section "504"

PROMISES TO KEEP

"No otherwise qualified handicapped individual — shall solely by reason of his handicap, be excluded from the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."



Section 504 of the Rehabilitation Act of 1973 speaks with bold language and holds out unlimited opportunities to the disabled. The Governor's Subcommittee on Barrier Free Design is pleased to assist you by suggesting these information resources. This brief bibliography of selected materials is designed to enable you and your agency/organization to come into full compliance with the lawwith a minimum of problems and on schedule, so that the promise of 504 can be a reality.

ACCESSIBILITY MODIFICATIONS. Ronald L. Mace, 1976. \$2.00. Order from: North Carolina Department of Insurance, P.O. Box 26387, Raleigh, North Carolina, 27611.

ANSI STANDARDS. American National Standards Institute, Inc. Currently being revised. For information contact: Dr. Edward Steinfeld, Project Director, Syracuse University School of Architecture, 118 Clarendon Street, Syracuse, New York, 13210.

HOW TO ACCOMMODATE WORKERS IN WHEELCHAIRS. Janet Asher and Jules Asher. Free. Order from: President's Committee on Employment of the Handicapped, Washington, D.C., 20210.

AN ILLUSTRATED HANDBOOK OF THE HANDICAPPED SECTION OF THE NORTH CAROLINA STATE BUILDING CODE. Ronald L. Mace and Betsy Laslett. 1974. \$2.00. Order from: North Carolina Department of Insurance, P.O. Box 26387, Raleigh, North Carolina, 27611.

INTO THE MAINSTREAM: A SYLLABUS FOR A BARRIER-FREE ENVIRONMENT. Stephen A Kliment. Free. Order from: Rehabilitation Service Administration, 330 C. Street, S.W., Washington, D.C., 20201.

ARCHITECTURAL ACCESSIBILITY
FOR THE DISABLED OF COLLEGE
CAMPUSES. Stephen R. Cotler and
Alfred H. DeGraff. 1976. Single copies
free. Order from: State University
Construction Fund, 194 Washington
Avenue, Albany, New York, 12210.

BARRIER FREE SITE DESIGN. HUD. \$2.30. Order from: Superintendent of Documents, U.S. Government Printing Office, Washington, D.C., 20402.

BUILDING WITHOUT BARRIERS FOR THE DISABLED. Sarah P. Harkness and James M. Groom, Jr. \$10.95. Order from: American Institute of Architects Publications Marketing, 1735 New York Avenue, N.W., Washington, D.C., 20006.

DESIGN CRITERIA. NEW PUBLIC BUILDINGS ACCESSIBILITY. Issued by General Services Administration. \$2.60. Order from: General Services Administration, Basic Service Center, Room 1447, 600 Arch Street, Philadelphia, Pa., 19106.

PEOPLE ARE ASKING ABOUT -DISPLAYING THE SYMBOL OF
ACCESS. Free. Order from: The
President's Committee on
Employment of the Handicapped,
Washington, D.C. 20210.

REPORT. National Center for a Barrier Free Environment. Bi-monthly. Single copies free. Order from: National Center for a Barrier Free Environment, 8 4 0 1 Connecticut Avenue, Washington, D.C., 20015.

MAKING COLLEGES AND UNIVERSITIES ACCESSIBLE TO HANDICAPPED STUDENTS. Compiled by State University Construction Fund. Free. Order from: President's Committee on Employment of the Handicapped, Washington, D.C., 20210.

TIMETABLE FOR SECTION 504 COMPLIANCE ACTIVITIES

The following dates are a reminder of the activity that those private agencies hospitals, schools, colleges, public agencies, and some doctors should be involved if they need to come into compliance with the "504" regulations.

December 2, 1977 *84.22(e)
Transition Plans for existing facilities.

June 2, 1978 *84.6(c)
Self-Evaluation of Current Policies and practices.

September 1, 1978 *84.33(c)
Free and appropriate Public Education

September 1, 1978 *84.3(k)(2) Expanded age coverage elementary & secondary education

June 2, 1980 *84.22(d)
Program Accessibility: Structural changes

Evaluation and Planning at Elizabethtown



Included in the membership of the committees for Planning and Evaluation of the Elizabeth town Habilitation Center are: Dr. William Gibson, Medical Director; Elizabeth Boggs, Ph. D.; William Graffius, Director State Easter Seal Society; James Umbrell, Union Representative; Hon. Kenneth Brandt, State Representative.

The Elizabethtown Committee for Planning and Evaluation held a public meeting on November 21, 1977 to hear the views of citizens concerning the future utilization of the Elizabethtown Habilitation Center. On the following day the Committee discussed the public input at their second of three scheduled meetings.

The committee was appointed by Secretary of Health, Leonard Bachman, to present a plan for the future of the Center to the legislature and the Governor by January 31, 1978. Included in the plan will be a complete utilization review of the Center, fiscal and medical audits, evaluation of the quality of professional services and the physical plant, and recommendations for the future direction of the Center's programs.

The Committee is impressed favorably with the quality and deciation of staff and the increased number of clients served over the past ten years with decreased length of stay, demonstrating improved medical management. This increased efficiency has resulted in an underutilization of the facility. The Committee's recommendations are expected to include increasing the availability of certain professional services at the Center, improving the physical environment, increasing the numbers of clients served, and further developing ties with universities to create internships for interdisciplinary professional training. The first draft of the plan is expected to be prepared in December. The Committee's final meeting will be January 4, 1977.

State Park Providing Handicapped Accessibility

Robert C. Peppel Park Superintendent Chapman State Park Clarendon, Pa,

During an eight (8) week program at Chapman State Park in the summer of 1977 the Youth Conservation Corp crew assigned to Chapman completed a project that will benefit all handicapped persons wishing to use the park. By the time they had finished with their work every facility in the park had been made accessible to the physically handicapped and some new facilities for the handicapped had been constructed.

Among the things they decided to do were:

-Create a permit system whereby handicapped drivers could use park service roads and specifically designated parking spots along these roads to easily reach specific recreation areas within the park. Where the driver was not the handicapped person, he could drive on the service road only long enough to drop off his handicapped passenger before returning to a regular public parking lot.

-Eliminate all steps, widen doorways, provide hand rails, and enlarge dressing rooms and toilet stalls to accommodate wheelchairs so that all buildings were accessible.

-Construct two (2) fishing piers for the handicapped, one of which also would serve as a boat dock.

-Provide adequate signing to inform the handicapped park user.

Eight (8) parking spots for handicapped drivers have been provided along existing service roads, near restroom facilities. A 12 x 12 foot fishing pier was constructed near the dam. A 8 x 24 foot combination fishing pier and boat dock was constructed adjacent to the boat rental facility. Picnic tables were rebuilt by putting new tops on them which extend two (2) feet beyond the end of the benches so that wheel chairs can roll right under the end of the table and the handicapped person becomes an integral part of the group around the table.

PENN STATE UNIVERSITY OFFERS 750 HOUR TRAINING PROGRAM IN THERAPEUTIC RECREATION

The Recreation and Parks Program of The Pennsylvania State University has received approval of The National Therapeutic Recreation Society to conduct the 750 hour training program for therapeutic recreation technicians. The University will offer the training as a certificate program consisting of 46 credits of classroom instruction and practical experiences. The certificate program will be conducted as a Continuing Education service of The College of Health, Physical Education, and Recreation. Upon successful completion of the training, graduates are eligible to apply for registration with N.T.R.S. as a Therapeutic Recreation Technician I.

This certificate program is structured to accommodate those currently in full-time employment and to meet the need for this type of training on a geographic basis throughout the commonwealth. The training will be coordinated by staff at University Park but will utilize eight branch campuses to conduct the training.

Initial coursework in the program is planned to begin in February or March 1978 at the various locations. Inquiries about the program should be directed to the Continuing Education Offices at the location listed above or to Ray West, Coordinator, 750 Hr. Training Program in Therapeutic Recreation, 267 Recreation Building, University Park, Pennsylvania 16802.

Governor's Child Advocacy Committee

To Focus on P.L. 94-142

by Donald Mathis
Executive Director
Commonwealth Child Development
Committee

Pre-school special needs children and the coordinated services that their handicapping conditions require will be the subject of a year-long examination by the Commonwealth Child Development Committee (CCDC). CCDC was established by Governor Shapp with the Governor's Office for Human Resources to plan, coordinate, and advocate for

children's services. The chairperson of CCDC is Dr. Gerald Fendrick, M.D., a pediatrician with Jefferson Medical College.

CCDC's Subcommittee on Early Childhood and Special Needs is concerned with the availability of programs for all preschool handicapped children. Subcommittee members represent the medical, direct service provision, state agency, and parent sectors. Nancy Heyman of the State Department of Education met with the Sub-committee regarding the impace of 94-142 on the services from the Department. Charlie Wall and Fred Davis spoke on the role of project CONNECT in the implementation of preschool Individualized Education Program (IEP).

In the future, the Subcommittee will meet with the members of the Department of Public Welfare's Offices of Mental Health and Mental Retardation in order to clarify how 94-142 will or will not affect MH/MR and PL 89-313 programs. CCDC staff will also meet with Dr. John Bartrain, M.D., Chairperson of the Health Task Force for the Implementation Committee, Of The Governors Conference On Handicapped Individuals.

At the conclusion of these meetings, the Subcommittee will set goals as to its role in coordination and advocacy of services for preschool handicapped children.

All CCDC and Subcommittee meetings are open to the public. The next Subcommittee meeting will be on January 18th at the Host Inn, Harrisburg, at 7 p.m. For further information, please phone Betty Roth or Rosemarie Richards at (717) 787-3489.

Citizenship is not a One-Way Street

Bill Kiser, of Winston-Salem, N.C., the Handicapped American of the Year, authors a weekly syndicated newspaper column, a weekly radio program, and edits a newspaper for the North Carolina Rehabilitation Association.

No, I am not a recent immigrant to the United States. But I am beginning to experience the joys and responsibilities that a new citizen often feels. A native-born American might well ask the reason for my elation. As I have had a severe cerebral palsy involvement from

birth, I have often doubted that I had full citizenship in these United States. While I was taught as a child to respect the law, my parents did not impart to me the fact that I was a political being with rights and responsibilities. To them, as to most people, the government was a reality with which one lived.

In early childhood, the nearest contact I had with politics was through one of my neighbors who was a clerk of the court. Every four years he would solicit the support of the neighborhood in his reelection, and listening to his children, I was led to believe that the world would surely come to an end if his sorry opponent ever won.

Shortly after high school I shocked the neighborhood and the voting official by pushing five or six blocks in my wheelchair to register to vote, and thereafter raised a few eyebrows on each election day by working my wheelchair into the line at the polls. My local voting official soon began to look for me and was always willing to help me mark my ballot.

I was fortunate that my voting place was located at a fire station that presented no architectural barriers. I have since learned that architectural barriers prevent many handicapped people from exercising their rights to full citizenship.

How can elected officials hope to improve the lives of handicapped people? Our efforts to gain better rehabilitation services, more employment opportunities, the elimination of architectural barriers, and the establishment of other human rights has given the elected official a new role.

While we still hope that doctors and scientists will discover new ways to alleviate our physical difficulties, we know that this is often dependent on government-sponsored research and treatment programs. My future, and the future of other handicapped people, depends upon understanding political leaders.

It is very significant that both major parties included special planks in their 1978 platforms with respect to handicapped people. The first White House Conference on Handicapped Individuals, held May 25 to 29 at the Sheraton Park Hotel in Washington D.C. was another important milestone in the political advancement of America's handicapped citizens.



THE GRAND STAND

VOL. I, NO. 5

GOVERNOR'S COMMITTEE FOR THE PHYSICALLY HANDICAPPED

JAN/FEB 1978

Results of the White House Conference

THERE WERE 3,522 RECOMMENDATIONS under 287 issues. Following extensive discussion the 800 delegates at the White House Conference on Handicapped Individuals voted and placed these recommendations in order of preference. The votes were then tabulated by computer.

The delegates almost unanimously selected by their vote a recommendation related to economic opportunity. This recommendation calls for rehabilitation specialists to receive education and training that would sensitize them to the special needs of all handicapped people who are being prepared for job placement.

The voting on recommendations reflected several major themes. These include:

- -A fully accessible transit system.
- -Education provided to health professionals, employers, rehabilitation personnel, and architects that will specifically prepare them to understand the total scope of accessibility-the full range of disabilities and their unique problems.
- -More active involvement by disabled persons on committees, boards, and



Milton Berkes, Governor's Special Assistant for Human Services met with consumer representatives from across the Commonwealth to inform them of the action being taken by Pennsylvania in order to comply with the 504 Regulations of the Rehabilitation Act of 1973. Nancy Landis, Interpreter for the deaf, from the Counseling Service for the Deaf, Inc. of Lancaster, providing interpreter service for those consumer present with impaired hearing.

advisory councils that provide services to meet their needs.

- -A systematic access to information about services and programs available to handicapped people.
- -Enlarged public awareness of the inclusion of handicapped people in all aspects of community life.
- -Increased employment opportunities through dynamic affirmative action programs, tax incentives for employers, and pre-vocational training of

handicapped people.

-More effective health care achieved through a team approach that would include family members with the health professionals.

The final report of the Conference were submitted to the President, and disseminated nationally in December.

Resolutions developed at the Conference were voted on by mail by the delegates. There were 156 resolutions and 142, or 91 percent, were passed.

THE GRAND STAND-PLANNER
504 State Street Building
Harrisburg, Pennsylvania 17101
John H. Snyder, Managing Editor
Margot Mor, Contributing Editor of the Planner

BULK RATE
U.S. POSTAGE
PAID
Permit No. 366
Harrisburg, Pa.